Evaluation of a dementia awareness programme in UK schools: A qualitative study

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Abstract

Objectives: 'Dementia Friends' is a programme used to raise awareness of dementia, developed by the Alzheimer's Society, which has been delivered across the UK to diverse populations, including adolescents. However, there is little evidence available with regards to adolescents' perceptions of the programme and its impact. This study aims to explore this in a group of adolescents from the south of England.

Design: Four focus group discussions

Methods: 30 adolescents aged between 11 and 16 were recruited from two schools in East Sussex, England. All had participated in a Dementia Friends session in the past month. Focus group discussions were transcribed, coded and themes were created using inductive thematic analysis.

Results: Four themes were identified: 1) perceptions and experiences of dementia, 2) outcomes and learning from Dementia Friends session, 3) reactions to the Dementia Friends session, and 4) identified future learning needs.

Discussion: Adolescents had generally positive opinions about Dementia Friends, particularly the interactive nature of the session. Whilst they felt participating in Dementia Friends improved their attitudes and knowledge, they were often left wanting to learn more. Future research needs to empirically evaluate the extent to which Dementia Friends may improve attitudes and knowledge of dementia.

Keywords: Schools, young people, knowledge, stigma**,** dementia awareness, dementia literacy

Introduction

Raising awareness of dementia is seen as key policy priority, both within the UK and internationally.[1–4] The Alzheimer's Society, a national third sector patient and carer advocacy group in England and Wales, has been a major advocate for raising awareness of dementia, in part through its Dementia Friends Initiative, which "*tackles the stigma and discrimination people with dementia can face globally*" [5] in a 45-60 minute awareness session led by trained volunteers. Each session covers five key messages about dementia (i.e. Dementia is not a natural part of ageing, Dementia is caused by diseases of the brain, It is not just about losing your memory, It is possible to live well with dementia, There's more to a person (with dementia) than the dementia), followed by individuals making a pledge to do a dementia-friendly action. The Dementia Friends initiative has been successfully rolled out, being the UK's "*biggest ever initiative to change people's perceptions of dementia*". [5] It was launched in the UK in 2013 with the target of reaching one million people by 2015, by 2018 there were over 2.5 million Dementia Friends in the UK. [6]

Inherently, educating young people about dementia is a positive aspiration. Theoretically, attitudes form at a young age and are more easily changed, but upon reaching adulthood these attitudes remain more stable.[9–11] Similar to mental illness,[12,13] negative and stigmatising attitudes towards dementia already appear to exist amongst adolescents.[14–17] Conceptually, education is seen as an important means of reducing stigma towards dementia,[18] and towards other mental illnesses.[19] Localised dementia awareness initiatives do exist aimed at adolescents and young people (e.g. Dementia4schools) though it is notable that there is often not rigorously evaluated. One exception being the Australian Kids4Dementia programme [20] which found a significant improvement to dementia attitudes in those who received Kids4dementia programme compared to those who were in the control group.

Despite the potential theoretical benefits of dementia awareness programmes, and limited evidence from other initiatives, it is still unclear whether Dementia Friends is effective in raising awareness, improving attitudes, and meeting information needs across groups. To our knowledge, there has been no published

literature about young people's involvement in the development or evaluation of Dementia Friends. Even within adults, there is limited evidence about the benefits of the Dementia Friends initiative. For example, Dementia Friends improved self-reported knowledge about dementia and confidence in engaging people with dementia in student nurses.[21,22]

In this study, we set out to explore adolescents' reaction to of a Dementia Friends information session, and how it affected their perceptions of dementia.

1. How does Dementia Friends training affect adolescents' attitudes and knowledge of dementia?
2. What do adolescents think about Dementia Friends sessions and their content?

Methods

Design

A series of Focus Group Discussions (FGDs) were completed to generate data for inductive thematic analysis. Methods are reported in accordance with Consolidated criteria for Reporting Qualitative research (COREQ) Checklist.[23] See Appendix A for the completed COREQ Checklist.

Participants and Setting

An opportunistic sample of two secondary schools (teaching ages 11-16) participated in the study. Schools geographically close to Brighton were prioritised, due to our collaboration with Brighton and Hove Dementia Action Alliance. Characteristics of the school were available from a government portal, and were correct as of April 2020 and reflect the 2018/2019 academic year. [24]

- School 1: Located in Brighton and Hove. Mixed gender, community school. Within the school, students whose first language is not English was below national average of mainstream secondary

schools (5-10%), whilst the number of students eligible for free school meal at any time during the past 6 years was also below national average of mainstream secondary schools (20-25%).

- School 2: Located in East Sussex. Mixed gender, community school. Within the school, students whose first language is not English was below national average of mainstream secondary schools (0-5%), whilst the number of students eligible for free school meal at any time during the past 6 years was also below national average of mainstream secondary schools (10-15%).

Working alongside teachers at the schools, classes of adolescents participated in the Dementia Friends sessions. Only adolescents who participated in the session, participated in this research. In recognition of the difficulties of lesson planning and classroom management, adolescents invited to participate in the research were selected by the teacher. Teachers were instructed to invite a mixture of male and female students with a range of academic abilities, but were asked to keep in mind that these adolescents would need to be confident enough to engage in the discussions. An *a priori* decision was made to complete four focus group discussions, or until thematic saturation occurred.

Thirty adolescents took part in four focus groups. Participant characteristics are presented in Table 1. No participants who were approached refused participation or dropped out.

Dementia Friends Session

The Dementia Friends session was led by an experienced "Dementia Friends Champion" (XX). A Dementia Friends Champion is a volunteer who tries to support people within their communities to improve the lives of people with dementia, through sharing information about dementia. Dementia Friends are trained to deliver Dementia Friends sessions. [25] As of April 2019, XX has trained over 1,400 Dementia Friends, which include young people. XX is a volunteer at the Dementia Action Alliance, a retired social worker, and has lived experience of caring for someone with dementia.

The Dementia Friends session had XX facilitate discussion amongst a class of adolescents, which covers five key messages:[26]

- Dementia is not a natural part of ageing
- Dementia is caused by diseases of the brain
- It is not just about losing your memory
- It is possible to live well with dementia
- There's more to a person (with dementia) than the dementia

Procedure

After the classes (approximately 30 adolescents in each) participated in the Dementia Friends session, the teacher identified groups of 6-8 adolescents to be invited to participate in the research. Parents/guardians of the selected adolescents were sent information about the research and provided consent for their child's participation. All adolescents were provided an information sheet describing the aims of the study and an opportunity to opt-out of the research, being informed that it was voluntary.

FGDs were run during class time within the school setting. The facilitator introduced the FGD and provided the group rules, and asked a series of questions to the group in a semi-structured format. Discussions were audio recorded, no field notes were taken. FGDs lasted approximately 30 minutes each.

FGDs were completed within a month following the Dementia Friends session (typically the following week). All FGDs were completed between January and March 2019.

Measures and Topic Guide

All participants were asked to complete a set of demographic information (e.g. age, gender, ethnicity) alongside their previous experiences of dementia, using an existing questionnaire.[16]

The topic guide was developed in collaboration with the research team, who have experience working with people with dementia (in clinical, research and care worker capacities) and children (in a research capacity). The questions broadly covered three key topics: 1) whether the Dementia Friends session affected their attitudes and knowledge, 2) what they thought about the current session, and 3) how the session could be improved. See Appendix B.

Analysis

Descriptive data (Mean, SD, frequency) of demographic information and previous contact were reported for each FGD and as a whole sample.

Audio recordings were transcribed verbatim by the facilitator of the FGDs, imported into QSR International's NViVO 12 software, and subject to thematic analysis. Two transcripts were initially independently coded by two researchers (XX and XXX). The two researchers then reviewed and compared the two coding frameworks, discussing differences and to ensure that no codes were missing. If differences were identified the two researchers discussed why this was the case, and whether this was superficial (e.g. choice in terminology) or something more complex, the two authors continued to discuss the frameworks until consensus was achieved. XXX continued coding the remaining transcripts.

Codes were then inductively grouped into themes.

Ethics and Rigour

All the FGDs were led by a single female researcher (XXX). XX has previous experience of facilitating FGDs in both adults and adolescents, and at the time of the FGD, was a Research Assistant in dementia. XXX has previous experience in the care sector. In three out of four FGDs, XXX was joined by a male researcher (XX), who has experience in running FGDs in adolescents. Neither the teaching staff, nor the

Dementia Champion (XX), were involved in the FGDs to ensure that participants could speak freely. The Dementia Champion (XX) was however given an opportunity to discuss the findings and review the transcripts, following the formation of themes. This allowed XX to provide insight and interpretation of the findings, without introducing bias within the data analysis. Participants were not consulted about the transcripts or provide feedback about the findings derived from the FGDs.

The FGD facilitators had no existing relationship with the participants, though they introduced themselves, described their job roles and the research aims. All participants were provided food and drinks prior to the start of the FGDs, to help create a social and relaxed environment. As participants for each FGD were recruited from a single class, therefore participants within each FGD had an existing relationship with each other. No formal incentives or reimbursement were supplied. However, participants may have felt motivated to participate as they would be taken out of their usual lesson to participate.

Ethical approval was obtained [XXXX XXXXX] Research Governance and Ethics Committee.

The data that support the findings of this study are available on reasonable request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Results

From the analysis four overarching themes were identified: 1) perceptions and experiences of dementia, 2) outcomes and learning experiences from Dementia Friends session, 3) reactions to the Dementia Friends session, and 4) Identified future learning needs. A coding tree is presented in Figure 1.

Theme one: perceptions and experiences of dementia

The first theme was related to adolescents' views and experiences of dementia in general.

Personhood

Participants had an overall positive perception of dementia and a positive outlook of people who live with dementia, which according to participants existed prior to the Dementia Friends session. Participants held the view that despite the impairments that people with dementia might have, it is possible to live well with dementia. Participants had a strong sense of personhood in those with dementia, they believed that people with dementia were still people who deserve to be treated the same as everyone else. Participants did not describe these views in relation any specific teachings or experience, and appeared to reflect a broader sense of personhood to all, not just dementia. Example quotes can be found in Table 2.

Sources of information

The main source of information for participants about dementia was the media, with some discussion that family and television commercials also provided information about dementia. The media information about dementia was seen primarily as negative and conveying an inaccurate picture of dementia.

Theme two: Outcomes and learning experiences from Dementia Friends session

The theme of outcomes and learning experiences encompassed participant perceptions of how the session changed their knowledge, understanding, and perceptions of dementia.

New understanding about dementia

Another subtheme identified was that participants did not fully understand what dementia was before the session or how dementia affects individuals. Participants highlighted the changes to their knowledge and understanding about dementia from taking part in the session. They learned that there are lots of different types of dementia, not just one or a small number. A great deal of discussion surrounded learning more about the way that memories are affected in dementia, and that dementia is not just about memory loss. The most salient point of discussion for participants was that they gained new understanding about the

feelings that people with dementia can experience, irrespective of the memory impairment they may have. This new understanding helped participants know more about dementia and what people are feeling, and that this would be especially useful for people who have interactions with people with dementia.

Changing perceptions towards dementia

Closely linked to new understanding, participants also discussed the ways that the session changed their pre-existing perceptions of dementia. There was a lessening of the negative perception of dementia with participants discussing that taking part in the session helped them feel more positive and empowered to visit and support someone with dementia. Because of the session they would know what to expect and have more understanding of what to do. The feelings of personhood and positivity that participants had were strengthened as a result of Dementia Friends.

Changing behaviour intentions towards dementia

Participants discussed the intention to spend time with and work with people with dementia in the future. Participants' willingness to spend time with people with dementia could be attributed in part to the level of empathy they felt toward people with dementia. Some participants stated that they would want people to visit and spend time with them if they had dementia so they are willing to do this for people now. When asked if they would consider working with people with dementia in the future participants showed some positivity toward this. They described feeling more inclined to work with people with dementia in the future because they now have more understanding about dementia and know what to expect when engaging with people with dementia.

Theme three: Reactions to the Dementia Friends session

This theme captured participants' general perceptions about the Dementia Friends session. Participants were able to recall the content of the session clearly. There was a great deal of positivity about the Dementia Friends session with participants being satisfied with the session, including its length, content and methods of teaching.

Satisfaction with the content of the session

There was an overall sense of satisfaction with the session, with conversations often being focussed on positive aspects of Dementia Friends rather than negative ones. Participants found the session to be interesting, understandable, and interactive. There was a great deal of satisfaction with and positivity of the content and delivery of the session, including the session facilitator. These factors were seen as making the session useful and containing the right amount of information that was interesting, engaging, and understandable for the adolescent participants.

Benefits of Interactive learning

The interactive elements of Dementia Friends are a pre-specified component of the initiative, and is central to all sessions.These interactive elements were perceived to be one of the most positive aspects of the session. Participants described that the interactive tasks in the session allowed everyone to get involved, and focus on what was being taught. This was seen as a more effective way of learning compared to more traditional methods of teaching (i.e. teacher lecturing and student notetaking, textbooks and pen-and-paper assessment), as it was better at helping participants remember the content of the session.

The benefit of the interactive nature of the session was particularly evident in one focus group that had recently had a talk about another topic. The talk had no interactive elements to it, participants described it as boring and stated that comparatively, the Dementia Friends session was more fun, and they were able to learn and remember more in comparison.

Satisfaction in the length of session

Overall the length of the session was seen as an acceptable and appropriate. The Dementia Friends sessions within this study lasted 50 minutes to 1 hour, though ultimately the length of time is dependent on how long it takes to cover the pre-defined content. Participants believed that the session was long enough to enable them to understand and remember the content of the session, but was not too long that people lost their focus or concentration. Again, when comparing the length of the Dementia Friends session with other talks, participants described the length as long enough to provide the needed information without becoming boring or with unnecessary information.

Theme four: Identified future learning needs

The theme of future learning needs captured participants' desire to learn more about dementia. Despite their satisfaction with the length and content of the session, participants discussed the changes that they would make to the session that would be beneficial to learning about dementia. This included adding in more content and more sessions.

Desire for more content

Participants discussed some of the ways that they would change the content of the session, this included more content they would like to have included, and changes to the content they would like to be made to improve their learning experiences. There was a desire to learn more information than was provided in the session and to learn more in-depth about the information that was provided. In particular, participants wanted to know more factual information such as the different types of dementia (above and beyond that multiple types of dementia exist), what causes dementia, the symptoms of dementia, and how to help

people in a practical way. There was a belief that this would enable participants to help others in the future, so that they could "spot" signs of dementia, especially in family members.

Participants were keen to learn from people with dementia. They believed that this would be better at raising awareness and a more emotive and impactful way of learning compared to more traditional methods. Learning from people with dementia or from others such as carers would provide a different perspective and have a greater impact on adolescents.

Desire for more sessions

Participants discussed their positivity toward having more sessions. This included having more sessions to accommodate the inclusion of extra content that participants had discussed, and being able to accommodate learning from others such as people with dementia. Their discussions also included having a refresher session that could recap the first session with the addition of the desired extra content. The timing of extra sessions was discussed with short time-periods between sessions (approximately two weeks) being seen as preferable.

How to help and engage people with dementia

Participants wanted to know how they could help people with dementia. Linked to the desire to learn more about dementia, this included how to deal with particular symptoms such as forgetting, and what they could do more generally to help such as giving to charity or volunteering in places like care homes. Participants also suggested some ways that they could help people.

Closely linked to helping people, participants showed a keen interest in learning how to engage with people with dementia. This included learning how to socialise with people with dementia and how to approach them in order to help them talk about and remember their day. There was also a sense of

wanting to know how to help in the community, such as helping to support local organisations such as hospices and care homes.

Dementia education should be available for all adolescents

The Dementia Friends session, and dementia education more generally, was seen as important to be available to everyone regardless of their past experience with dementia. For example, participants believed that everyone in school should have the same information provided to them because it will help safeguard against changes in the future when they may have a relative with dementia.

Discussion

This study aimed to explore the opinions of adolescents, and impact of, an on a one-off dementia information session, Dementia Friends. Four themes appeared to form as a result of the FGDs, related to existing perceptions and experience of dementia, learning and outcomes from Dementia Friends, their reaction to the session, and their future learning needs.

Using this method, we are able to describe a more in-depth understanding of the impact of Dementia Friends, as perceived by the adolescents who participated in it. It challenged and corrected misinformation that they had gleaned from the media. This supports previous research that has found that most of adolescents' experiences of dementia come from media, such as TV and movies.[15,16] The negative portrayal of dementia, or use of dementia as an insult, within western media has been highlighted.[27,28] In this study, after the session adolescents were able to identify that the media portrayal of dementia was generally negative, and that this was the first opportunity they had to formally learn about dementia. Adolescents were able to recall that they viewed people with dementia were still people (i.e. personhood) prior to Dementia Friends session, but the content reinforced these beliefs. This indicates that Dementia

Friends might align with the opinion of young people with previous experience of dementia who feel that dementia education should instil views of personhood.[14] We believe that the data presented here are the first empirical demonstration of the potential value of Dementia Friends for adolescents.

Despite adolescents recognising there were different information needs depending on whether they had previous dementia experience, there was the view that the Dementia Friends session was informative. However, Dementia Friends was perceived as only the start of their learning journey, as many participants were left wanting to learn more. Whilst there was variation in the type of additional information participants wanted, many requested further details about risks and risk reduction, and the practicalities of how to help and engage with those with dementia. The causes and risks dementia have previously been flagged by UK adolescents as an interesting topic to learn about.[32] Understanding risk factors of dementia at a young age might be particularly important considering that modifiable risk factors for dementia exist across the lifespan. [33]

There are important limitations to the research presented here. First it was carried out in just two schools in one area in one country. Second, only one Dementia Friends Champion (XX) gave the training. Third, the participants for the groups were chosen, without any formal criteria, by the teachers. Therefore, at most we can conclude is that the themes reported here only reflect the findings of a small selection of adolescents, no efforts were made to triangulate the findings with other sources. Fourth, the content here represents the views at a single time-point, several weeks after a Dementia Friends session. It is possible that adolescent views about the session, and dementia more generally, may be different over a longer period, particularly once contextualised with additional experiences of dementia (e.g. dementia in the media). As such, future research should consider exploring the long term impact of Dementia Friends on attitudes towards dementia. There are however a number of strengths. First, it is positive that staff within participating schools were highly motivated to offer the Dementia Friends session to their students, thus increasing the likelihood that their students were also engaged with the session. Second, all selected participants completed the FGD. Finally, having a single Dementia Friends Champion (XX) run all the

Dementia Friends sessions ensured that there was consistency between classes in terms of teaching style and knowledge. However, it is important to recognise that the quality of the session will differ depending on the confidence, experience and abilities associated with the Dementia Friends Champion. Within the current study, XX had both lived experience of dementia and was an experienced Dementia Champion, which may be reflected in the positive feedback provided by the adolescents.

There is still a need to understand whether the self-reported improvements to attitudes and knowledge reported here and elsewhere, reflect quantifiable improvements. FGDs may lead to participants to exaggerate, down play or withhold their opinions depending on the social context, [36] whilst people tend to overestimate their abilities in social and intellectual domains.[37] Understanding the effectiveness of Dementia Friends will provide evidence for policy makers and educators to adopt such an initiative, but also consider its value compared to other dementia awareness initiatives, and consider the potential influence of certain participant characteristics. For example, within Kids4demenita programme, the authors were able to provide an effect size for the initiative to improve dementia attitudes, and also able to identify adolescents who had not heard of dementia prior to the session benefited more.[20]

Educating adolescents about dementia within secondary schools (aged 11-16) does not appear to be common practice.[38] However, the use of a one-off dementia awareness class, such as Dementia Friends, may be acceptable to schools that have limited time and resources to introduce a more comprehensive alternative. The need to combat stigma towards dementia is pressing. The Dementia Friends session is seen as enjoyable and engaging by adolescents, which is essential in the success of any awareness programme. It is positive that adolescents felt there were benefits to their knowledge and attitudes towards dementia, however future research is needed to quantify the value of such interventions.

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Conflicts of Interest

No potential conflict of interest was reported by the authors.

Author contributions

XXXXX wrote the first draft of the paper, planned the study, collected the data, performed the analyses, and revised the paper. XXXXX collected the data, revised the paper, and contributed to the analysis. XXXX facilitated the Dementia Friends session, contributed to the analysis, and revised the paper. XXXX helped plan the study and revised the paper. XXXXX helped plan the study and revised the paper. XXXXX helped plan the study and revised the paper. XXXXX helped plan the study and revised the paper.

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Table 2. Summary of themes, subthemes and participant quotes

Themes	Example quotes
Theme one: Perceptions and experiences of dementia	
Personhood	• *"I think you can live well with it. It's not a really, really terrible thing, because like, you can still do everyday things, like people like us. But like you just, sometimes can't remember things right, can't do things properly" (Female, Focus group 2)* • *"They're just normal people, they have dementia but there's no like, they're not different and people with dementia should be treated the same way, and they should be treated with care because obviously they can forget stuff, and they're just people so they're just the same as us, there's nothing different with them" (Female, Focus group 1)* • *"Even if you do have dementia, you're still a person, you are, well, you're still human" (Male, Focus group 1)*
Sources of Information	• *"[the media] doesn't portray a good like equal sided opinion of it [dementia], so it was good to have the woman [EJ] come in to like, both opinions of it, it can still be negative on the media" (Female, Focus group 4)*
Theme two: Outcomes and learning experiences from Dementia Friends session	
New understanding	• *"I thought it was really informative, there was obviously some parts that I think a few people knew in the class but I think the majority of it, because it's not really spoken about a lot and I think it, a lot of people learnt a lot from it, whether it was like, little parts of the illness or, the fact there's lots of different types, how it affects you, because I think most people thought it just affected how you thought, like I especially didn't know that it could really affect your everyday life like trying to do simple tasks like your mobility and stuff" (Female, Focus group 4)* • *"it gave me more like awareness of it [dementia], because before like I just thought it's just that you forget things, but like with that class I learned that they do forget things but they remember like old memories and they keep their feelings and everything" (Female, Focus group 2)* • *"because my Gran has dementia, I could, because of that, I can like know more things about what she's feeling" (Male, Focus group 2)* • *"I didn't know you like you still remember like the emotions so I thought that you just forget like everything" (Female, Focus group 4)*
Changing perceptions towards dementia	• *"It made me feel more positively about the people that have it" (Female, Focus group 2)* • *"Like before the thing [dementia awareness class], I thought like dementia was like an illness it was just a terrible thing, and now I kind of realized it's not that bad" (Male, Focus group 2)*

	• *"After the session I feel like I'd find it much easier to go see someone with dementia and what it's like, because I know kind of what I'd be expecting and if I saw them doing certain things I'd know how to deal with it a bit more than before" (Male, Focus group 3)* • *Participant: "If someone's like living with dementia you still see them as who they are not just what they have, like if someone has dementia you don't just see them as someone suffering from dementia, they're still a family friend, a parent, a carer, like they're still the same person, you may just need to adjust what you say or how you live around them, but they're still the same person". Interviewer: "do you think you had that opinion before or did it change because of the session". Participant: "I had that opinion already but it came a bit more stronger like after" (Female, Focus Group 3)*
Changing behaviour intentions towards dementia	• *"I would like to [spend time with people with dementia] as well, like, and then it might, because we might learn about what dementia is and it might help them, it might help us like, understand if they forget something and I'd just like to spend time with them a bit more" (Female, Focus group 1)* • *"I'd want more friends to come and see me, so I wouldn't mind spending time with someone with dementia" (Female, Focus group 1)* • *"yeah I would work with them [people with dementia] because I know more about it than I did, it's like easier to understand how they're feeling" (Male, Focus group 2)*

Theme three: Reactions to the Dementia Friends session

Satisfaction with the content of the session	• *"The staff [facilitator] are really like nice and trying to engage everyone like with the games, and I think people that wouldn't usually like get involved I think they were trying to listen because she was really genuinely quite a nice person, friendly, and it came across" (Female, Focus group 4)* • *"I think everyone should receive the same because they might feel, it might like help people that have people with dementia, it might make them feel like they can open up, but then it could help other people in the class who don't have a family member with dementia, and like, they might not know a lot about it, and then they might be put in another session because people might think they have someone with dementia so they know, or they might not 'cause [trails off] (Female, Focus Group 1)*
Benefits of Interactive learning	• *"everyone was kind of focused and involved, she kept everyone kind of not just slipping out of concentration everyone was focusing on what she was talking about" (Male, Focus group 3).*

Theme four: Identified future learning needs

Desire for more content	• *"I think possibly like, if they could go more in depth on how it happens, and not just the… effects, but more about the causes" (Male, Focus group 2)*

	• *"because she [EJ] was saying about some of the signs of it, like the early signs of it like losing your short term memory and stuff and I think it's good for you to, because then you can look out for your family members, try kind of like sense how they're going" (Female, Focus group 4)* • *"I think that [being taught by someone with dementia] would be quite an emotional way for it to be brought across, I think that would really affect the students more than just someone who doesn't have it, but obviously that might be more difficult for the person to do it than someone else just coming up and telling them about it" (Female, Focus group 4)* • *"It [being taught by someone with dementia] would probably reach more people than if it was a teacher" (Male, Focus group 4).*
Desire for more sessions	• *"Personally, I think it would be good to have a refresher session because they can tell you about how people get it or like, what goes on like in their mind and loads of other stuff about it as well" (Male, Focus group 2)* • *"maybe if we had like two more sessions in it or something and like, maybe one could be like with a person with dementia and the other could be like how to like help people" (Female, Focus group 1).*
How to help and engage people with dementia	• *"what you could do just as one person, um like actually do, obviously we know um part of dementia friends is like an awareness but like, that's just almost an awareness, what actions you could take if you had a family member with dementia" (Female, Focus group 4)* • *"actively how you could help that person and or other people in your community maybe anywhere local who does like, because obviously you have places like the hospice, or like nursing homes, is there anywhere like around us a lot of people with dementia can get help from that we can like support" (Female, Focus group 4)*
Dementia education should be available for all adolescents	• *"I agree that everyone should have the same lessons because even if you don't have a family with dementia now then you can't say the same for in the future when you haven't had the same lessons so you can learn all about it" (Female, Focus group 1)* • *"later on they may have a family member who has dementia and then not having that lesson may really like make them stuck or whatever" (Female, Focus group 1).*

Table 1. Participant characteristics split by focus group.

	Group 1 (n=8)		Group 2 (n=6)		Group 3 (n=8)		Group 4 (n=8)		Total (n=30)	
	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)
Age	12.4 (0.5)		12.2 (0.4)		14.6 (0.5)		14.50(0.53)		13.5 (1.25)	
Gender: Male		2 (25.0%)		4 (66.7%)		5 (62.5%)		4 (50.0%)		15 (50.0%)
Ethnicity: White British		6 (85.7%)		5 (83.3%)		7 (87.5%)		8 (100.0%)		26 (89.7%)
I have come across people living with dementia: Yes		5 (62.5%)		6 (100.0%)		7 (87.5%)		7 (87.5%)		25 (83.3%)
I have watched TV shows or movies: Yes		5 (62.5%)		4 (66.7%)		6 (75.0%)		6 (75.0%)		21 (70.0%)

I have looked after someone with dementia: Yes	3 (37.5%)	2 (33.3%)	3 (37.5%)	1 (12.5%)	9 (30.0%)

Appendix A

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Title (1)
Occupation	3	What was their occupation at the time of the study?	7
Gender	4	Was the researcher male or female?	7
Experience and training	5	What experience or training did the researcher have?	7
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	8
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	8
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7-8
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	5, Table 1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	7-8
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	7, Appendix B
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	6
Duration	21	What was the duration of the inter views or focus group?	6
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	8

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	7
Description of the coding tree	25	Did authors provide a description of the coding tree?	7, Figure 1
Derivation of themes	26	Were themes identified in advance or derived from the data?	4, 6
Software	27	What software, if applicable, was used to manage the data?	7
Participant checking	28	Did participants provide feedback on the findings?	7
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Table 2
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Table 2, 8-14
Clarity of major themes	31	Were major themes clearly presented in the findings?	8-14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	15

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Page numbers are accurate for the accepted, non-type edited, manuscript.

Appendix B

Example of focus group questions:

1. What did you think of the dementia awareness class?
2. Did you think the information was useful?
3. Can you describe your perspectives on dementia?
4. Is there anything more you would like to learn about dementia? If so, what?
5. How has the dementia awareness class affected your views about people with dementia?
6. Would you consider spending more time with people with dementia, or working with them in the future?
7. Was the session long enough?
8. Would you be interested in a “refresher” session?
9. How could the session have been improved?